How Vermont Taught the World about Rehabilitation and Recovery in People with Severe and Persistent Psychiatric Problems

Dr. Courtenay M. Harding

(former nurse at VSH,

a psychologist trained at UVM and

now a professor of psychiatry)

PLAN FOR PRESENTATION

- Reveal the transformation process at VSH from custodial to remarkable
- Follow the roller coaster journey
- Discuss the impact of rehabilitation in reclaiming lives
- Show evidence of significant improvement and recovery in serious and persistent psychiatric disabilities

Vermont Mental Health Care in the Early Years

What We Overcame

1790 to 1850 – The OVERSEER of the POOR in VT

- **His Options**
  - **Absolute authority over the "poor, vagrant, idle, and disorderly persons, idiots and lunatics."**
  - **Send them to the Poor Farm, Jail, Alms Houses**
  - **"Fetter, shackle, or whip ….the inmates."**
  - **"Could auction off the poor and their families in a public place."**
    - **History of Public Welfare in Vermont**

More Overseer Job Description

- Was permitted to “dispose of them with no regard for the family ties.”
- “ Doctors were often untrained apprentices who doubled as clergymen, barbers, civil officers, and plantation owners.”
- Job actually lasted in Vermont until about 1966 & changed to Dept of Social Welfare

Vermont State Hospital

- Built in 1890 on a French Fortress design
- By 1950s had 1300 beds in a state of only 377,000 people
- Families told to grieve over loved ones as if they had died
- People were disconnected from families, communities, and received few letters or packages from home

The VSH Environment

- Rarely reviewed for S/S after 2 years
- 3 hot meals and a cot
- "A 'good' patient was to be dull, harmless, and inconspicuous"
- Ludwig, 1971
- Insulin shock
- Electroshock without relaxers
- People had no rights
- Dead patients buried with numbers only or used as research

Vermont State Hospital

- 1951 – “ I saw our fellow human beings, our fellow Vermonters, herded together closer than a Vermont farmer would think of keeping cattle in a barn.”
- “Beds are less than a foot apart”

  - Kincheloe & Hunt 1989, pg. 68

More on VSH in 1951

- **“There is no privacy and women are herded into a single bathroom facility which does nothing to maintain dignity and self respect.”**
  - **Kincheloe & Hunt 1989, pg. 68**

George W. Brooks, MD in the mid-1950s

- As a young psychiatrist
- Director of Research at VSH
- Member of UVM Psychiatry faculty

Vermont State Hospital

- Only state hospital in state … very important to know
- Anyone with a problem ended up there
- Dr. Brooks received one of the first Smith Kline French fellowship to study the effects of the new drug Thorazine

Results of the Thorazine Trial

- Tried it on most of the back ward patients and 178 people got better and left !
- 269 people in back wards still stuck there after a modest response to the drug after 2 ½ years

Symptom Profiles of people left in the back wards in 1955

- Delusions
- Hallucinations
- Affective Flattening
- Poverty of Speech
- Avolution
- Loose associations
- Tangentially
- Word Salad
- Attention Deficits
- Impaired Memory
- Problems with Information-Processing
- Bizarre posturing
- ▲motor activity
- ▼awareness of environment

Original Functional Descriptions of the Vermont Cohort - 1955

- 16 years duration of illness
- 10 years being totally disabled
- 9 years from first hospitalization
- Middle-aged
- 5 of 6 single
- Impoverished
- Less than 9th grade education
- Isolated from family & friends
- Slow, poor concentration
- Impaired memory

Original Functional Descriptions of the Vermont Cohort in 1955

- Touchy
- Suspicious
- Temperamental
- Unpredictable
- Over dependent on others to make minor decisions
- No goals or unrealistic ones
- Peculiarities in
  - Appearance
  - Speech
  - Behavior
- Constricted sense of time, space, and other people
- Poor social judgment
- Little or no initiative

“My ignorance saved me.” admitted George Brooks

- “I really didn’t know what to do to get them out of the hospital.”
- “I asked ‘What do you need? What do you need next? What do you need next?’”

He also read Maxwell Jones (1952) and Harry Stack Sullivan (1953) on therapeutic communities and milieu therapy

Some Ingredients of Therapeutic Communities

- People considered to have “innate core of goodness which could be restored to health by the proper environment and care.”
- Horizontal not hierarchical authority
- Focus on education and work
- Shared decision making
- Interdependence as a goal
- Living-learning opportunities in every social interaction and crisis

The Vermont Team Phase I and II

- George Brooks
- William Deane
- Robert Lagor
- Donald Eldred
- Barbara Curtis
- Vera Hanks
- Marjorie Taylor
- The Aides
- Rupert Chittick
- Francis Irons
- The 269 people still stuck in the back wards
- A joint venture between DMH and DVR

THE VERMONT STATE HOSPITAL REHAB PROJECT

- Driven by patients and clinicians in an unusual collaboration
- Staff trained in psych & rehab skills
- Developed a model of rehab + self-sufficiency + community integration led to recovery
- Became a widely copied demonstration project

VERMONT'S MODEL DEMONSTRATION REHAB PROGRAM 1955-1965

(Chittick et al, 1961)

- Developed much of rehabilitation and lots of community psychiatry
- Was highly innovative
- Done with small grant (OVR)
- Always positive messages about recovery

VERMONT'S MODEL DEMONSTRATION REHAB PROGRAM 1955-1965

(c) (Chittick et al, 1961)

- Peer supports
- Patient gov. & Graded Privileges
- Outpatient clinics
- Rehab housing
- Range of social supports
- Case management
- "Activities of Daily Living"

VERMONT'S MODEL DEMONSTRATION REHAB PROGRAM 1955-1965
(Chittick et al, 1961)

- Health watch
- Approaches to family a disaster
- Group therapy
- Social skills & problem solving
- Connection to natural community supports

VERMONT'S MODEL DEMONSTRATION REHAB PROGRAM 1955-1965

(Chittick et al, 1961)

- Voc rehab – in/out
- Assessment, training, placement & after job supports; job/person match
- Low but therapeutic dose of meds

Key factors from staff perspective

- Effective use of multidisciplinary team members
- Blending change with continuity and commitment
- Reduction of anxiety and panic
- Re-aquainting person with real world
- Providing economic security and social links
- Maintaining commitment
- Learning from asking

10 Years of Supports Offered

- 1955 to 1965
- Same clinicians in both places (Therapeutic Community and outside community)
- Titrated Supports – step down and into outside community
- Welcome to return to Therapeutic Community for short R & R
- Welcome to come back for dinner

Some Early Results

- By 1960 for the group which was supposed to grow old and die in the hospital .....
- 83% were out of hospital
- 53% never came back
- Of the 47% who came back in the early days two thirds were rereleased
- Only 15% never made it back out

FORWARD MOVEMENT TOWARD RECOVERY-BASED SYSTEMS OF CARE

- "ACTION FOR MENTAL HEALTH"

1961!

(AMA, APA, Amer. Acad of Neurology and Dept of Justice)

Action for Mental Health - 1961

- "The fallacies of 'total insanity' 'hopelessness' and 'incurability' should be attacked and the prospects of recovery and improvement through modern concepts of treatment and rehabilitation emphasized."
- Why has it taken over 50 years to really implement this imperative?

Vermont Really Did Teach the World about Rehabilitation

- George Brooks was awarded the Presidential Medal by President Dwight Eisenhower !
- Clinicians came from around the world to see what Vermont had accomplished

Phase II – Continued Follow-Along 1960-1965

- Led by Drs. Brooks and Deane
- Clinical Team continued to provide outpatient care, a range of housing, and social supports in the community
- Huge amount of continuity of care

More findings for PHASE II by 1965

- Single status still dominated
- Social activities used community facilities
- Work was often in sheltered employment

Phase II Research

- 170 people were part of Phase II research project
- Revealed that many people still struggling with meds and rehab

THE SHOCK AT THE END OF PHASE II in 1965

- **"Two thirds of the cohort could be maintained effectively in the community *IF* sufficient transitional facilities and adequate aftercare were given."**
- **BUT staff could see**
- **"no foreseeable end"**

GRANT MONEY RAN OUT

PEOPLE WERE CONNECTED TO NATURAL SUPPORT SYSTEMS IN COMMUNITY

TEAM WITHDREW TO HOSPITAL

Phase III & IV
the 1980s and 90s

What happened to all these people 15 years later?

And 32 years after their 1st admission ?

PHASE III and IV

- The longest study of deinstitutionalization in US
- The longest study of a matched comparison (rehab vs. no rehab)
- One of the longest studies of schizophrenia in world

THE VERMONT LONGITUDINAL PROJECT

Now 100 + multidisciplinary investigators worked and/or volunteered to help us do the tightest study of design and methodology of all similar studies

PRIMARY TEAM
for Phase III
in Vermont

UVM PSYCHIATRY

Courtenay Harding, PhD
George Brooks, MD
Paul Landerl, MSW
Carmine Consalvo, PhD
William Deane, PhD
Janet Wakefield, PhD
Andrea Pierce

UVM BIOSTATISTICS

Taka Ashikaga, PhD
Rod McCormack, PhD
Shiva Gautam, PhD
Suzanne Ledoux
Dorothy Myer

YALE PSYCHIATRY

John Strauss, MD
Alan Breier, MD

CONSULTATION WITH TEAMS - INSIDE VERMONT

- **VERMONT STATE HOSPITAL:**

- **George Brooks, MD**
- **William Deane, PhD**
- **Robert Lagor, VR**
- **Barbara Curtis, RN**
- **Peter Laqueur, MD**
- **Father Louis Logue**

- **UVM PSYCHOLOGY:**

- **Richard Musty, PhD**
- **George Albee, PhD**
- **Jon Rolf, PhD**
- **Larry Gordon, PhD**
- **David Howell, PhD**
- **Tom Achenbach, PhD**
- **Heinz Ansbacher, PhD**

EVENTUALLY EVEN A BIGGER TEAM EFFORT - INSIDE VERMONT 2

- UVM College of Medicine
  - Barry Nurcombe, MD
  - Thomas Achenbach, Ph.D.
  - Janet Mikkelsen, MSW
  - William Woodruff, MD
  - Stanley Miller, MD
  - Edgar Forsberg
  - Alice Mower
- Trinity College
  - Patricia Reid, BSW
  - Joan Jarvis, BSW
- Vermont DMH
- Vermont DVR
- Vermont Council of CMHCs
- Individual CMHCs
- Smith College
  - Susan Childers, PhD
- Adelphi College
  - Irene Bergman, Lynn Forrest & Mary Herzog

It was at a time when everyone was arguing with one another

- We flew a Swiss flag
- Researchers were neutral parties
- Everyone worked with us
- We were very grateful

MORE TEAM MEMBERS

- VSH RECORD ROOM:
- Meredith Rogers
- Connie Harthorn
- SECRETARIES ACROSS
- INSTITUTIONS
- Andrea Pierce
- Viola Graham
- Molly Clark
- Florence Sherman
- Chris Estey
- Nancy Ryan

- UVM LIBRARY
- Carolyn Fox
- Sally Rogers
- UVM GRANTS
- Stephen Stoddard
- Louise Chandler
- Rosemary Rathbun
- UVM SPONSORED PROGRAMS
- Patricia Armstrong
- Karen Inman

AN ENORMOUS TEAM EFFORT - OUTSIDE VERMONT

HARVARD:

- Jane Murphy, PhD
- Brendan Maher, PhD
- Robert Shapiro, MD
- Alan Gelenberg, MD
- Bonnie Spring, PhD
- George Vaillant, MD
- George Gardos, MD

COLUMBIA PHS:

- Joseph Fleiss, PhD

YALE :

- John Strauss, MD
- Alan Breier, MD
- Edward Zigler, PhD
- Malcolm Bowers, MD
- Victoria Seitz, PhD

UNIVERSITY OF PITTSBURGH:

Gerard Hogarty, MSW

UNIVERSITY OF BERN SWITZERLAND:

- **Luc Ciompi, MD**

MORE TEAM EFFORT - OUTSIDE VERMONT

WASHINGTON UNIVERSITY:

- Lee Robins, PhD

CHESTNUT LODGE:

- Tom McGlashan, MD

UNIVERSITY OF MARYLAND:

- Lee Bachrach, PhD
- Stan Herr, JD

NIMH:

- Loren Mosher, MD
- Sam Keith, MD
- Judith Turner, PhD
- Nancy Miller, PhD
- Jack Maser, PhD
- Larry Chaitkin, PhD
- Alice Lowery

32 YEAR FOLLOW-UP (ranging to 62 years after 1st admission)

- Funded by the National Institute of Mental Health
- 97% Found and/ or Accounted For of 269
- 5 + Hours Of Interviews & 2x
- Structured Interviews And A Life History
- Blinded Interviewers, Record Abstractors, And Diagnosticians
- Reliably used current Dx criteria
  - Harding et al, Amer J. Psychiatry, 1987 a and b

Ten Embedded Studies - 1

- Cross-Sectional (How are you today & the past month)
- Longitudinal (Time since release & Life Chart)
- Parametric Characteristics of the VSH Pop in 1954
- Verinform Study

Embedded Studies - 2

- Study of Deceased Population
- The Rediagnostic Study
- The LIFELINE Validity Study
- The Commissioner's Requested Study
- The Maine-Vermont Matched Comparison (Rehab vs No Rehab)
- Policy Changes and Program Implementation Across ME and VT

Protected Rights

- The Right to Informed Consent
- The Right to Refuse
- The Right to only answer questions they wished to answer
- The Right to Privacy
- The Right to Confidentiality
- Unusual for the time before HIPAA
- Worked with Stan Herr, JD then at Harvard Law

So what did we find?

ANOTHER
BIG SURPRISE !

62 to 68% of people, who were expected to grow old and die in VSH, reclaimed their lives!

Very Stringent Criteria for Recovered

- No enduring symptoms,
- No odd behaviors,
- No further medication,
- Living in the community,
- Working, and relating well to others

- **Significantly improved**
  - Recovered in all areas but one
    - Harding et al, 1987

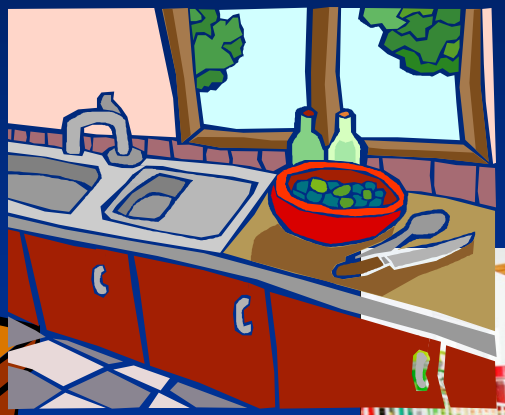
THE MAJOR CROSS-SECTIONAL FINDINGS

- 68% Displayed Little Or No S/S
- 64% Had Less Than 2 Rehospitalizations In 20 Years Post Release
- Average Of Less Than 2 Years In Hospital Post Release For All

Initial Report of CURRENT drug use early in Cross-Sectional Interview

- 16% had no further prescriptions
- 84% reported using their prescriptions

But tales of Use, Misuse and Non-Use of prescribed medications emerged



They showed us drawers and pantries full of unused medications !!

CONFESSIONS ABOUT SELF- MANAGEMENT OF NEUROLEPTIC DRUGS FROM 1968 ONWARD

- 16% No Prescriptions
- 34% No Use of Drugs Prescribed
- 25% Targeted Self-Use of Drugs (off mostly – on when feeling "shaky" then off again)
- 25% Precise Use of Drugs (afraid of lowering dose)

MORE MAJOR FINDINGS-3

- l.5% Involved With The Law
- 81% Able To Care For Self
- 40% Employed
- 20% Volunteer Work

MORE MAJOR FINDINGS-4

- 54% Using CMHCs - 46% Out of System!
- 67% Of Those Med Checks Only Every 3-6 Months
- 68% Had Moderately Close To Close Friends – Reconstitution Of Social Skills

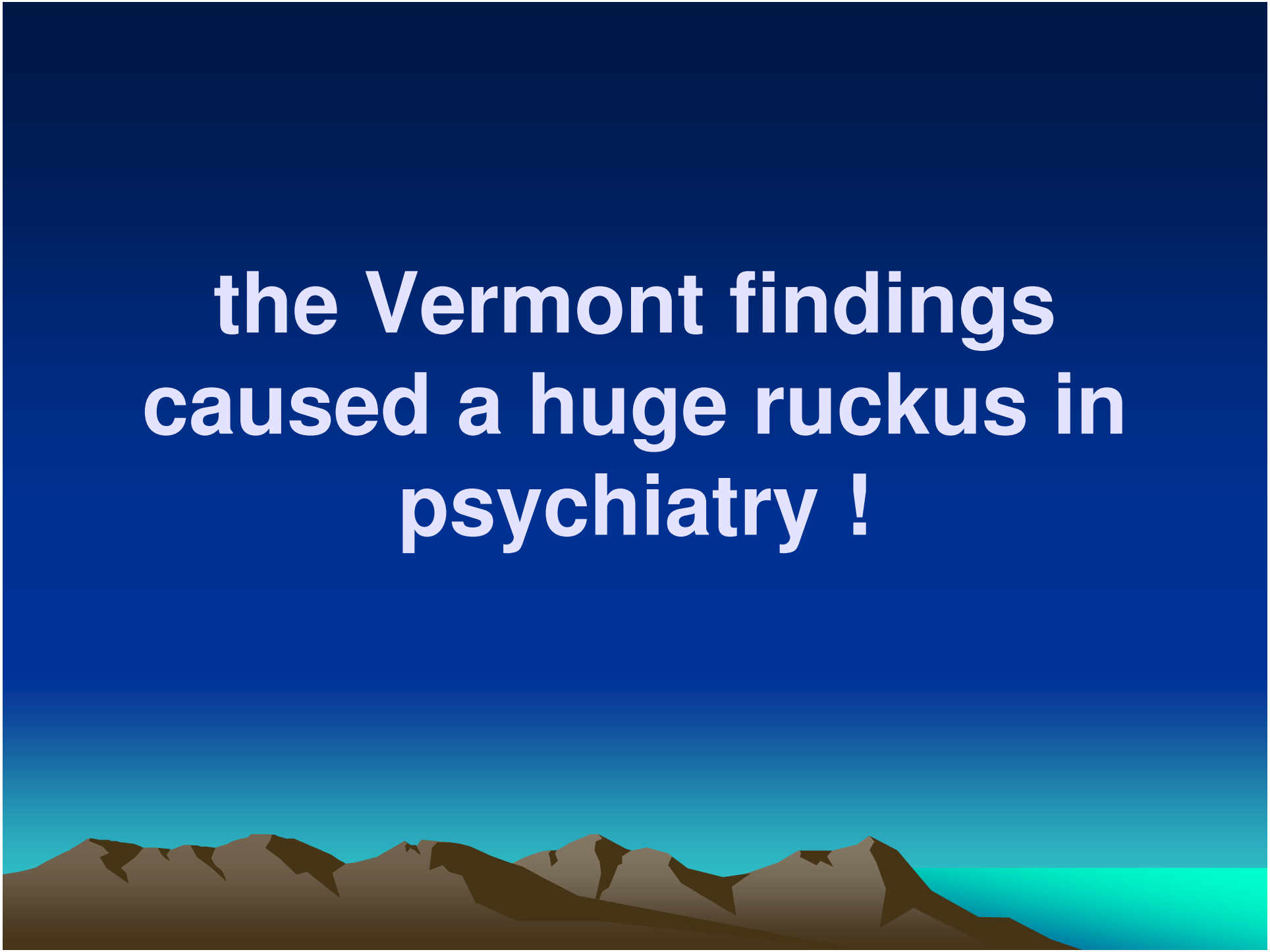
What Vermonters said helped the recovery process .....

- Decent housing, food, and clothing #1
- People with whom to be
- Ways to be productive citizens
- Ways to manage medication and symptoms
- Individual treatment planning & case management
- Integration into the community

What the Vermont subjects said made the most difference in their struggles toward recovery ……..

- **"SOMEONE BELIEVED IN ME"**
- **"SOMEONE TOLD ME I HAD A CHANCE TO GET BETTER"**
- **"MY OWN PERSISTENCE"**

- **Translates to hope and hope connects with natural self-healing capacities**


the Vermont findings
caused a huge ruckus in
psychiatry !

PROGNOSIS AS DEFINED BY DSM III - 1980

- **A complete return to premorbid functioning is unusual-so rare, in fact, that some clinicians would question the diagnosis.**

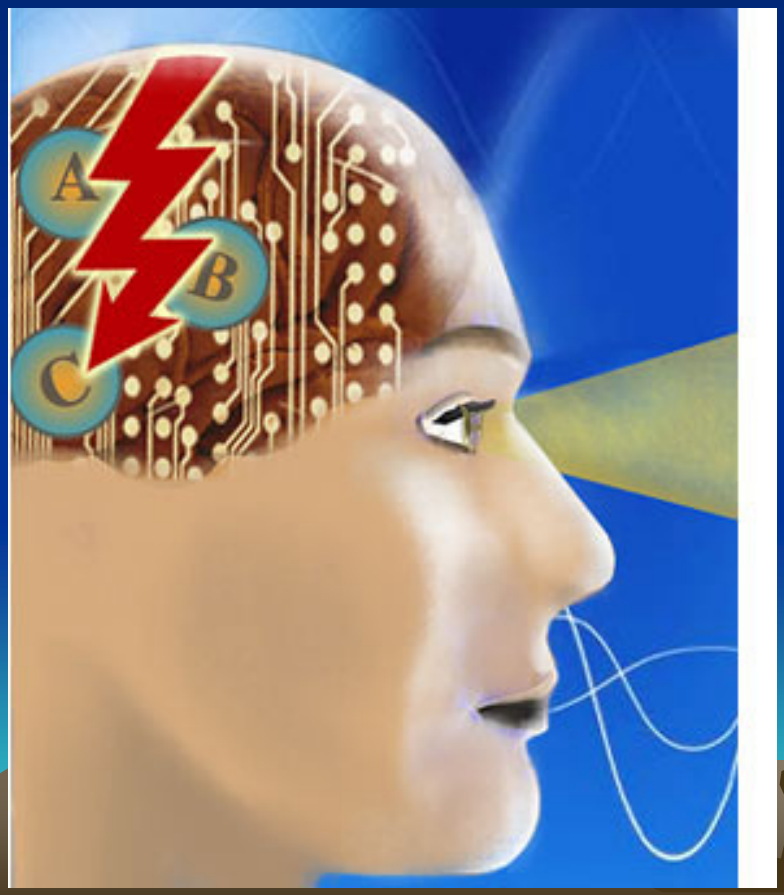
- **However, there is always the possibility of full remission or recovery, although the frequency is unknown. The most common course is one of acute exacerbations with increasing residual impairment between episodes.**

I was yelled at a lot in the 80s and 90s

1) "They must have been misdiagnosed."
2) "They must all be Affective Disorders."
3) "They are not like my patients who are much sicker."
4) Unaware of their own "clinician's illusion" (Cohen and Cohen, 1984)

Why have we consistently and persistently underestimated consumers of services?

Applying the principles of “BLINK” by Malcolm Gladwell (2005)



“Blink” is what happens

when you see someone and in an instant decide what you think about that person. It is also called “jumping to conclusions.”

Here is a metaphorical example using the blizzard of snow we had in Boston this year……..


Many people become
invisible under the blizzard of
diagnostic labels

Did that model demonstration rehab program really help people dig out of the blizzard of serious and persistent illness and disability?

THE MAINE STUDY TEAM #1
Phase IV

- MICHAEL DESISTO, PhD
- PRISCILLA. RIDGWAY, MA, PhD
- ALAN MCKELVEY, MSW
- CHRIS SALAMONE, MSW
- MARG FULLER, MSW
- MILLARD HOWARD, MA
- ROY ETTLINGER, MHA
- WALTER LOWELL, ED.D
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- W. SCHUMACHER, MD
- ALAN GELENBERG, MD
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- ANN DEWITT
- KEV CONCANNON, MSW
- ROBERT GLOVER, PhD
- JOHN LECASE, EngScD

THE VERMONT TEAM WHO WORKED WITH THE MAINERS

- C.M. HARDING, PhD
- P.D. LANDERL, MSW
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- SUZANNE LEDOUX
- J. PANDIANI, PhD
- ROD COPELAND, PhD
- JOHN PIERCE
- VASILIO BELLINI
- ELLEN RECTOR

VERMONT - MAINE COMPARISON (a)

- MATCHED SUBJECTS
- MATCHED CATCHMENT AREAS
- MATCHED TREATMENT ERAS
- MATCHED DIAGNOSTIC CRITERIA
  - DeSisto, Harding, et al, 1995

VERMONT - MAINE COMPARISON (b)

- MATCHED PROTOCOLS
- INTRA-PROJECT RELIABILITIES
- INTER-PROJECT RELIABILITIES
- BLINDNESS
- ONLY ONE IN LIT
  - DeSisto, Harding, et al, 1995

THE VERMONT – MAINE COMPARISON FINDINGS (1)

- VERMONT MODEL

- REHABILITATION
- SELF-SUFFICIENCY
- COMMUNITY INTEGRATION
- Av. 32 years
- 97% found

- MAINE MODEL

- MEDICATIONS
- ENTITLEMENTS
- STABILIZATION
- MAINTENANCE
- Av. 35+ years
- 94% found

THE VERMONT – MAINE COMPARISON FINDINGS (2)

- WIDE HETEROGENEITY
- BETTER COMMUNITY FUNCTION
  p.<0.001
- MORE WORK
  p<O.0009
- LESS S/S p< 0.002

- MODEST HETEROGENEITY
- LESS COMMUNITY FUNCTION
- MUCH LESS WORK
- MORE SYMPTOMS
- (DeSisto, Harding et al, Bri J of Psychiatry, 1995)

THIS IS WHY WE NEED TO HAVE REHAB OPTIONS…1…

- **The Vermonters were the most impaired with the most dire prognoses and they had the best outcome…**

VERMONT MAINE COMPARISON FINDINGS (3)

- **VERMONT SYSTEM:**
  - **COMPREHENSIVE/**
  - **COORDINATED**
  - **MISSION CLEAR**
- **MAINE SYSTEM:**
  - **UNCONNECTED & SPARSE**
  - **MISSION CONFUSING**

DeSisto, Harding et al, Bri J of Psychiatry, 1995 a and b)

THIS IS WHY WE NEED TO HAVE REHAB OPTIONS…2…

- **The model of rehabilitation, self-sufficiency, and community integration worked in combination to helped achieve the best results for everybody.**

Vermont taught the world about rehabilitation and recovery again !

- Recovery was never in the vocabulary for schizophrenia until it started to creep in by mid-1990s
- Now all 50 states have declared recovery missions and visions with pockets of excellence here and there
- Canada, Australia, New Zealand
- 11 European countries
- 9 Asian countries including China

Are we the only ones to find such results?

9 other studies of two and three decades of follow-up from across the world have found almost exactly the same thing: From 46 to 76% of people have gotten their life back!!

Please Note:
Shorter follow-up studies have also found significant improvement and recovery as early as 3 to 5 years! You do not have to wait 2 to 3 decades to get better

Vermont Influenced the world! as usual

- All 50 states have declared recovery visions and missions with pockets of excellence here and there across the map
- Canada, New Zealand & Australia
- 11 European Countries
- 9 Asian Countries (under serious consideration) including Beijing

TAKE HOME MESSAGES

- Even very impaired people can and do significantly improve and even recover
- The ideas behind Therapeutic Communities and “Evidence Based Processes” seem to help people reclaim lives from serious psychiatric problems

Take Home Messages (2)

- See and work with the person behind the diagnosis, disability and disorder
- Believe in recovery even if you can’t see it

REMEMBER THE VERMONT MODEL WAS: REHABILITATION, SELF-SUFFICIENCY AND COMMUNITY INTEGRATION

Vermont can lead the world again !

I look forward to learning about what you do next!

A Special Thank You

- - Most importantly – Thank you to the Vermont participants and their families, significant others, children, friends, clinicians, parish priests, all the players from the community, and the state …….
- Who opened their doors, their lives, and our minds


and
many thanks for bringing
me home again!